



Building a Collaborative Biomedical Network

Question and Answer Session from the caBIG® 2010 Annual Meeting Tuesday, September 14, 2010

Thomas P. Sellers, MPA

Thank you, Ken. Susan, that was a tremendous presentation. I've got to say I'm a little humbled and intimidated to be following a founding mother.

And my approach is and what I'm going to talk about is probably a little bit different than what Susan presented to you because I want to talk more about care and how high-quality care will generate an empowered group of patients and survivors who do want to participate in research and who do want to make a difference. As Ken mentioned, I'm a cancer survivor, an 11-year prostate cancer survivor, but I've also been a caregiver. My mom died of lung cancer at age 51 back in 1980 and my dad died of brain cancer, and I'm an only child so I've been the caregiver long distance as well as the patient. And I know that I have a vision that it is important for patients and caregivers to be actively involved in research and in their own care in order to improve the quality of care for everyone.

So just a little background. The National Coalition for Cancer Survivorship is nearly 25 years old and was founded by a group of primarily founding mothers who came together in 1986 and have been at the forefront of cancer policy advocacy for this nearly 25 years. And the work has really laid a foundation for the survivorship discipline that has culminated in, especially during the decade of the 2000s, a series of Institute of Medicine studies on the quality chasm and lost in transition survivorship studies. So all of these have been focused on establishing survivorship as a discipline and as a goal. So our mission is to advocate for quality cancer care for all Americans.

So there are two big words in that mission statement: advocate—or two big concepts: advocacy and quality cancer care. When we look at what quality cancer care is, we really do go back to the crossing the quality chasm study that was done by the IOM and look at the six elements that they identified as being the key points for quality cancer care. But of all those elements, I think the one that I'm most focused on and that NCCS is most focused on is patient centeredness, the importance of developing care that is patient centered and creating a healthcare environment that is focused on providing patient-centered care which, in practice, means that communication between patients and their medical team should be greatly improved, that the care needs to be coordinated, it needs to be comprehensive, and it needs to really cover the entire survivorship continuum from diagnosis through the balance of cancer care. And, in fact, this is how NCCS defines survivorship which is through the survivorship continuum, beginning at diagnosis and through treatment and into the transition to post-treatment cancer care or to planning for end of life.



Planning and coordination is really the backbone of that high-quality care so that we look to see a treatment plan that describes the kinds of symptoms that you might have and what sorts of palliative care you may do to manage those symptoms that gives you a treatment summary at the end of the treatment so you know exactly what they've done to you and then provides you with a post-treatment survivorship care plan that tells you about what sorts of late effects, second cancers, or recurrences might be in your future as a survivor of the treatment that you've been through.

So if that's quality care, what is advocacy from our perspective? And we actually, as an organization, really work to define advocacy in our quality cancer care advocacy across the continuum and our imperatives for quality cancer care that were published in the late 1990s. So we focused on self advocacy which is teaching individuals to advocate on their behalf with their family and their medical team, community advocacy which is really building the capacity to help others while you are understanding ways to encourage patient-centered care, and public interest advocacy which is really trying to change the laws and work with the policy makers to effect policy change at the national level. And that's what we try to do. We want to advocate for quality cancer care across the entire survivorship continuum and across the advocacy continuum.

And if we can be fairly successful at this—and right now I think there is a tremendous and unique opportunity for us to be successful which is why we're here—there are things going on that really can help us. We have the challenge and the opportunity of healthcare reform being implemented that will hopefully drive changes in both the delivery and systems for pain for cancer care. There are, as Ken mentioned, incentives for the adoption of electronic health records that can really be useful in building the infrastructure for patient-centered care. Now building the technological infrastructure for patient-centered care is necessary but it's not sufficient. You may have seen the *Health Affairs* column a couple or three weeks ago or in last month where they talked about how do you a build patient-centered policy and what is patient-centered care. And, in fact, technology is an important part of delivering patient-centered care, but it's more like a hygiene factor. You've got to have it there but it's not in and of itself enough to generate patient-centered care. And then you also have the proliferation of patient portals, the work that Ken has been doing with caBIG®, patients like me, and a whole variety of portals that are out there that can engage patients in their own care in ways that will both support quality care and be able to support the kind of research that needs to be done.

So we need to take advantage of whatever opportunities and challenges are out there, and we feel that the way to do that is by influencing any agency, any individual,,any organization that will be able to have an impact on the quality of care. So you work with development of guidelines and quality measures with folks like ASCO in the National Quality Forum, work on regulatory changes with CMS, you work on evidence-based standards with organizations like the Commission on Cancer, there are whole bunches of different ways that we can do that. But two examples that I want to give that NCCS is focused on is how do you implement a new technology that'll be helpful and what are some ways that we can actually bring power to the patients.



Was it something I said?

Ken Buetow, Ph.D.

You brought down the house.

Thomas P. Sellers, MPA

I brought down the house lights. That's okay. It's much easier now for anybody who wants to take a nap early in the morning to do it and I won't notice a thing.

One example of technology and innovation is a collaboration that the NCCS has been engaged in with the UCLA Cancer Center survivorship program, WellPoint, and Genentech which is called The Journey Forward. And what we've attempted to do there is to develop a tool that will make it easier for medical professionals to develop survivorship care plans for their patients under the idea that if you've got folks like the Commission on Cancer and ASCO and everybody else saying you really need to do care planning, let's make it easy for the members and the folks who are out there treating patients, in fact, to do that. So we've actually developed a PC-based tool call the Survivorship Care Plan Builder that is built on ASCO templates and surveillance guidelines and that has developed a regimen library that makes it easy for doctors to identify and to list out the regimen of care in the treatment summary. And it produces a plan that is available to the patient, either in patient or electronic form, and currently has something like 3,700 users across the country.

So we're trying to take a small step forward in getting patients and medical professionals engaged in providing that kind of planning that will hopefully lead to quality care. We've got a lot of work left to do. Clearly, with the broader adoption of electronic health records, we need to figure out how to integrate care planning into electronic health records adopted. And, in fact, we're not biased about this, we don't think that this is the only solution. We will advocate for integration of care planning tools into any system of electronic health records that will really be there to ensure that there is coordination between the primary care and the specialty docs and access to the vital information that patients need in order to be aware of what the future may bring to them.

A second example is how we try to bring power to the patient. And that is a program of NCCS that's called the Cancer Survival Toolbox which is currently an audio learning tool that is a self-learning program that really focuses on building core competencies in six basic areas: communicating, finding information, making decisions, solving problems, negotiating, and standing up for yourself. This is an evidence-based intervention that was developed in collaboration with the Oncology Nursing Society, the National Association of Social Workers, and the Association of Oncology Social Workers and that was validated by a series of focus groups and surveys with patients to ensure that these, in fact are the skills that patients need to have in order to be more engaged in their care on an annual basis. And we do also have this tool available on iTunes. But in talking about the future we know, for example, to do outreach to minority groups, broadband access is going to be generated in a lot of cases through smart phones more than through PCs. And if we



want to reach at targeted minority populations, we need to be developing how we're going to deliver skills like this through smart phone applications and through other technologies, whether it be video or otherwise. So in 2011, in fact, it's a high priority for NCCS to begin to migrate this content which is already evidence based into applications that will reach a broader range of people. So we'll continue to distribute some number of hard copies and we're doing about 35,000 a year, but we also intend to begin to distribute this kind of information and this type of skill development through the newer technologies that are available to us.

So we've got these opportunities and challenges. We've got some tools. We've got patients who are learning skills. We've got technology that can help to build survivorship care plans. If we do all this stuff and we actually make it happen, is it going to make a difference? Well, NCCS has just recently completed an online survey of nearly 1,250 of our constituents, 41 percent of whom, in fact, were survivors. And in that survey we found exactly what Dr. Love has found in her work which is that patients and survivors are hungry to participate in research and to be engaged in taking care and taking control of their own healthcare. And not only that, once you have the opportunity to manage your personal health information, even though there's not a lot of access to do that yet, you are much more interested in participating in research studies or providing your information to researchers where we found 82 percent of the survivors were willing to do that.

So if we can take advantage of the opportunity to bring together the technology, the other tools, new technologies, and empowering patients, tools to help providers, and we actually end up with a patient-centered system of care that has everybody working together, this is a system of healthcare that will be characterized by improved communication. And that means that we will be able to have patients who will generate the questions that need to be solved and who will be able to better interact with their medical teams and understand the answers to the questions that they're getting and to engage in active participation and shared decision making, greater adherence to the treatments that are available, and who will continue to want to participate in research.

So we're not out there recruiting the Army of Women, men, or otherwise, but we are out there trying to develop a much more highly-educated and empowered patient population. And that's really the focus of what NCCS is trying to do and how we hope to take advantage of the emerging technologies that are coming out that can benefit patients.

Thank you very much.

Speakers:

Ken Buetow, Ph.D.

NCI Center for Biomedical Informatics and Information
Technology (NCI CBIIT)

Thomas P. Sellers, MPA

National Coalition for Cancer Survivorship